

Residents' Rights

**for People in
Intermediate Care Facilities
for the Developmentally Disabled**

**As a resident of an
intermediate care
facility for the
developmentally
disabled in Illinois,
you are guaranteed certain
rights, protections and privileges
according to State and Federal law.**



Rod R. Blagojevich
Governor



Charles D. Johnson
Director

1.

Your rights to safety and good care

Your facility must be clean and stay at a healthy temperature.

You must not be abused by anyone — physically, verbally, mentally or sexually.

Your facility must not physically restrain you unless other less restrictive ways to keep you safe have been tried, have not worked and the use of a physical restraint is in your individual program plan (IPP).

You may be given medicine intended to change your mood or how you think only with your permission and only as part of an overall plan designed to change or remove the problems for which the medicines are given.

Medicine used to control your behavior may only be used when any potential harmful effects of the medicine are less than the harmful effects of your behavior.

2.

Your rights to participate in your own care

Your facility must develop, and revise as necessary, an individual program plan (IPP) which states all the services your facility will provide to you and everything you are expected to do. Your facility must make reasonable arrangements to meet your needs and choices.

You and your parent or guardian are to participate in the individual program planning conference. If you are **under 18 years old**, you and your parent or guardian are to participate.

You have the right to choose your own doctor. You will have to pay the doctor yourself unless Medicaid, your insurance plan or Medicare will pay the doctor bill.

You are in charge of taking your own medicine if your individual program plan says that you are able to do so.

You have the right to complete information about your medical, developmental and behavioral condition and all treatments in a language that you can understand.

You have the right to refuse treatment. If you refuse a treatment, your facility must tell you of other possible treatments and tell you what may happen because of your refusal.

You have the right to make a Living Will or a *Durable Power of Attorney for Health Care*, so the facility will know your wishes if you can no longer speak for yourself.

You may refuse to participate in any experimental treatment.

Your facility must allow you to see your medical records.

Your facility may not require you to work without pay.

You have the right to make visits, trips, or vacations with your family, friends or legal guardian.

You have the right to move out of your facility after you, your guardian, or — if you are a minor — your parent, gives the administrator, qualified mental retardation professional (QMRP), nurse, or doctor written notice that you plan to move.

3.

Your right to privacy

Your medical and personal care are private. Facility staff must respect your privacy when you are being examined or given care.

Facility staff must knock before entering your room.

Your facility may not give information about you or your care to unauthorized persons without your permission, unless you are being transferred to a hospital or to another health care facility.

You have the right to have private visits at any reasonable hour. This includes visits with family, close friends, legal guardians, and advocates. The only exception is if your interdisciplinary team finds that the visit would be wrong for you.

Your facility must answer letters and phone calls from your family and friends and encourage them to visit you unless you do not want them to visit or your interdisciplinary team decides that the visits would be wrong for you.

You may ask any visitor to leave your personal living area.

You have the right to make and receive phone calls in private.

Your facility must deliver your mail to you promptly, and promptly send mail out for you. Your facility may open your mail with your permission.

If you are married, you and your husband or wife have the right to share a room unless no room is available or your doctor has said you cannot share a room for medical reasons.

4.

Your rights regarding your money

You have the right to manage your own money or to receive training from your facility to improve your ability to manage your money. Your facility may not require you to let them manage your money or be your Social Security representative payee.

You may ask your facility to manage your personal money for you.

If your facility manages your money,

...it may spend your money only with your permission.

...it must provide a record of all money put into or taken out of your account if you, your parent (if you are under the age of 18), or your guardian asks.

...it must give you an itemized written statement of your account transactions once every three months.

...it must put your money in a bank account that earns interest for you, if you have more than \$100 in your account.

If you die, your facility must give your family, or whoever is in charge of distributing your property, a final accounting of all of the money left in any account which the facility manages for you.

5.

Your personal property rights

You have the right to keep and wear your own appropriate clothing and to participate in choosing new clothing.

You may keep and use your own property.

You have the right to expect your facility to have a safe place where you can keep small valuables which you can get to daily.

Your facility must try to keep your property from being lost or stolen. If your property is missing, your facility must try to find it.

6.

Your rights in paying for your care and getting Medicaid

If you are paying for some or all of your care at your facility, you must be given a contract that says what services are provided by the facility and how much they cost. The contract must say what expenses are not part of the regular rate.

You have the right to apply for Medicaid to help pay for your care. Your facility must not make you promise not to apply for Medicaid.

If you get Medicaid, the facility may not make you pay for anything that Medicaid pays for. The facility must give you a written list of what items and services Medicaid pays for, and those for which you could be charged.

7.

Your rights to stay in your facility

You have the right to live in your facility and receive training to meet your needs, as stated in your Individual Program Plan (IPP). Once you no longer need the services of an ICF/DD facility, you may not need to live in an ICF/DD facility any longer.

You have the right to keep living in your facility, unless your facility forces you to move because you are dangerous to yourself or others, for medical reasons, because you have not paid or are late paying your bill, or because your facility closes.

You cannot be forced to leave your facility because you are applying for Medicaid or you are on Medicaid.

If your facility wants to force you to move, you must be given a written notice 21 days before the day it wants you to move. The notice must tell you why your facility wants you to move and how you, your guardian or your parent, if you are under 18 years of age, can appeal to the Illinois Department of Public Health.

Your facility must give you the forms you need to appeal, and a stamped, addressed envelope for you to use to mail your appeal to the Illinois Department of Public Health.

You have the right to ask Equip for Equality, which is the federally mandated and Governor designated Protection and Advocacy System for people with physical and mental disabilities in Illinois, for self-advocacy assistance in appealing your facility's forcing you to move. Call **1-800-537-2632** (Voice) or **1-800-610-2779** (TTY).

If you appeal to the Department of Public Health, usually your facility cannot make you leave until the appeal is decided.

Before your facility can transfer or discharge you, it must provide preparation and orientation to be sure that your discharge is safe.

You must be allowed to return to your facility after you are hospitalized or go home for a therapeutic home visit, unless your facility gives you written notice as described above.

8.

Your rights as a citizen and a facility resident

Your facility must let you see reports of all inspections by the Illinois Department of Public Health from the last 5 years.

You do not lose your rights as a citizen of Illinois and the United States because you live in a long term care facility.

If a court of law has appointed a legal guardian for you, your guardian will exercise your rights for you.

If you have named an agent under a Durable Power of Attorney for Health Care, your agent may exercise your rights for you.

You have freedom of religion. At your request, the facility must make arrangements for you to attend religious services of your choice. The facility may not force you to follow any religious beliefs or practices and cannot require you to attend any religious services.

You have the right to vote for the candidates of your choice.

You have the right to participate in social and community activities.

You have the right to participate with other residents in the Resident Council. Your facility must respond to concerns raised by the council.

You have the right to meet with a representative from Equip for Equality, the Long Term Care Ombudsman Program, community organizations, social service groups, legal advocates, and members of the general public who come to your facility. Representatives of these groups may come to your facility to provide you with services, tell you about your rights, or help you assert your rights.

You have the right to present grievances to your facility and to get a prompt response. Your facility may not threaten or punish you in any way for asserting your rights or presenting grievances.

You have the right to present grievances to outside organizations and advocates including the following agencies:

Equip for Equality for persons with mental illness or developmental disabilities at **1-800-537-2632** (Voice) or **1-800-610-2779** (TTY);

Long Term Care Ombudsman at **1-800-252-8966** (Voice & TTY); and

Illinois Department of Public Health at **1-800-252-4343** (Voice) or **1-800-547-0466** (TTY).

If the rights presented in the booklet are not uniformly and consistently applied within your care facility, the following actions are suggested:

1 Define the problem. Writing it down may help make clear exactly what has happened and why it is wrong. When did it happen? (Give times and dates, if possible.) Who was involved or saw the incident? Ask questions of others who may be involved or know about the problem.

2 If it seems appropriate, talk the problem over with the staff responsible for taking care of you. Find out the facility procedures for resolving problems or concerns. If this does not seem like a good idea, or if you are not satisfied after you do, talk with the QMRP and then the QMRP can request that the situation be brought to the attention of the interdisciplinary team.

3 Ask for assistance from the Resident Council. The Council may present complaints on behalf of a resident to any person it considers appropriate.

4 If you or the Resident Council needs help solving the problem, you may want to ask Equip for Equality for assistance. Equip for Equality is the agency named by the Governor to provide protection and advocacy for persons with devel-

opmental disabilities or mental illness. You may call them at:

Equip for Equality
1-800-537-2632 (Voice)
1-800-610-2779 (TTY)

5 Contact the Long Term Care Ombudsman Program for assistance. The Long Term Care Ombudsman Program offers confidential help to older people who have questions, concerns, and/or complaints regarding the care they are receiving in their long term care facility. Call them at:

 Long Term Care
**Ombudsman
Program**
1-800-252-8966 (Voice & TTY)

6 Illinois has a formal Central Complaint Registry in the Department of Public Health. If you think your facility is violating your rights or those of your fellow residents, you can make a complaint against them. The Department of Public Health will investigate your complaint and if a violation is found, the long term care facility will be cited and corrective action will be taken.

Central Complaint Registry
1-800-252-4343 (Voice)
1-800-547-0466 (TTY)

Residents of facilities other than ICF/DD facilities have different rights than the rights listed in this brochure. To obtain a copy of the *Residents' Rights for People in Long Term Care Facilities* brochure, call the Long Term Care Ombudsman at **1-800-252-8966** (Voice & TTY).



421 East Capitol Ave., #100
Springfield, Illinois 62701-1789
217-785-3356 • FAX: 217-785-4477
www.state.il.us/aging/

Senior HelpLine: 1-800-252-8966 (Voice & TTY)
8:30 a.m. to 5:00 p.m., Monday through Friday

The Illinois Department on Aging does not discriminate in admission to programs or treatment of employment in programs or activities in compliance with appropriate State and Federal statutes. If you feel you have been discriminated against, call the Senior HelpLine at 1-800-252-8966 (Voice & TTY).

PRINTED BY AUTHORITY of the STATE OF ILLINOIS 5M (9/94), 10M (5/95, Rev. 5/03) *Recycled Paper*
Printed by the Illinois Department of Public Health with dollars from civil money penalties.